PAA

PSORIATIC ARTHROPATHY ALLIANCE

Liz Lynne MP — *David Chandler Director/Founder PAA* — *John Marshall MP*

Background:
John Dart - D.E.B.R.A
John & Margaret Ray - Disability Times
Mr Alistair Burt MP
David & Cath Uings

Centre:
David Congdon MP
Opening talk

Prof Chris Griffiths
Dr A. White
David Chandler

Mr Alistair Burt Minister for disabled — *Mr David Congdon MP* — *Ms Marjorie Johnson APBI*

Ms Elizabeth Ross
Clinical Ass. Immunology
St. Barts Hospital

Professor Chris Griffiths
Dermotologist
Hope Hospital. Manchester

OFFICIAL CHARITY LAUNCH
Thursday, 18th April 1996
Jubilee Room
Westminster Hall, House of Commons
London.

The Psoriatic Arthropathy Alliance is a registered national Charity dedicated to raising awareness and helping people with Psoriatic Arthritis and it's associated skin disorder known as Psoriasis.

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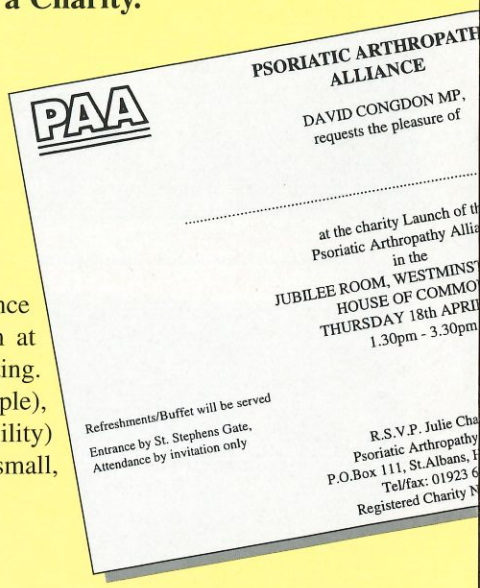
Tel/Fax: 01923 672837
Registered Charity No: 1051169
Company Limited by Guarantee No: 3055414

DID YOU KNOW?

Up to 3 million people in this Country will have the skin disorder Psoriasis - BUT DID YOU KNOW that recent studies show that up to 25% of people with Psoriasis could go on to develop PSORIATIC ARTHRITIS, if this staggering figure is correct it could mean that up to 750,000 people with Psoriasis could have this double sworded debilitating part of the condition!

The PSORIATIC ARTHROPATHY ALLIANCE is launched as a Charity.

WHAT MAKES FOR A SUCCESSFUL LAUNCH PARTY?


PAA

PSORIATIC ARTHROPATH
ALLIANCE

DAVID CONGDON MP,
requests the pleasure of

at the charity Launch of t
Psoriatic Arthropathy Allia
in the
JUBILEE ROOM, WESTMINS
HOUSE OF COMMO
THURSDAY 18th APRI
1.30pm - 3.30pm

Refreshments/Buffet will be served
Entrance by St. Stephens Gate,
Attendance by invitation only

R.S.V.P. Julie Cha
Psoriatic Arthropathy
P.O.Box 111, St.Albans, H
Tel/fax: 01923 6
Registered Charity N

Some would say the ambience and the setting. Others would ask who was there, yet again others would say the buffet or the speeches. . .

On every one of these counts we have to admit that the launch of the Psoriatic Arthropathy Alliance as a registered Charity on 18th April 1996, was an outstanding success. The Jubilee Room at Westminster Hall in the House of Commons provided an impressively gilded and heraldic setting. The launch was attended by Alistair Burt (Minister of State for Social Security and Disabled People), David Congdon MP, Liz Lynne MP (Lib Democrat Spokesperson on Social Security and Disability) and several others from the House. The buffet provided was excellent - just the right amount of small, delicious eats. The speeches authoritative, witty and equally important, relatively brief.

"AN IMPORTANT AND NEGLECTED AREA OF CARE"

David Congdon's opening speech set the scene. Describing the P.A.A as providing support in an important and indeed neglected area of care. David Congdon went on to express the hope that charitable status will help "towards a greater understanding of PAA. David also paid tribute to those who founded the P.A.A., describing them as people who say when they see an obstacle "How can we overcome it?

Professor Christopher Griffiths, Hope Hospital, Manchester, made the point that PA affects a lot of the population. He quoted John Updike, a lifelong sufferer from Psoriasis "SPREAD ACROSS THE BODY LIKE LICHEN ON A TOMBSTONE". For Professor Griffiths "Morbidity" was the main problem, the low quality of life" which made many people feel that almost any other on-going condition, such as asthma, would be preferable "Since stress" he continued "makes it worse, the whole condition can become a vicious spiral". There was no cure in sight as yet but what could be hoped for was a better understanding of PA through research.

"THE CINDERELLA OF THE RHEUMATIC DISEASES"

Dr Anthony White, Consultant Rheumatologist, Royal Free Hospital, London, described PA as "the Cinderella of the rheumatic diseases". PA doesn't even have the social cachet that gout has". As PA takes a differing form in different patients,even diagnosis can be difficult. Dr.White also explained that GP's can have problems in diagnosing various aches and pains when there was little psoriasis but a major joint problem. The answer lay he felt, in better education, especially of medical students and in research, especially into the mechanics of the arthritis. he regretted that at present not a great deal of work is going on and he saw "great scope for expanding research in this area".

A LAUNCH FOR ALL

So who was the party for? It was for everyone who has PA. It was an important step in the process of getting various messages across to our legislators and to our doctors and consultants. The event attached the attention of key people and of the press - Disability Times, for example, ran a full page in their May issue all about the P.A.A. entirely due to this launch party!

The fact of charitable status will also give fresh impetus to fund-raising and sponsorship, helping the P.A.A. to increase awareness of PA, to campaign for further research and to provide encouragement and assistance to an increasing number of people in the future.

Article kindly written by Mr John Ray.
May 1996

The PAA exists to: RAISE AWARENESS, SUPPORT, EDUCATE, PROMOTE, ADVOCATE, CAMPAIGN, INFORM.

"In the face of adversity and pain in this Alliance there will always be friendship, support and a listening ear."

THE BIRTH OF A CHARITY

How David and Julie Chandler mobilised help and support for people with Psoriatic Arthritis

Two years of suffering in silence

SIX YEARS AGO David Chandler was diagnosed as suffering from psoriatic arthropathy. The blow was so shattering and the implications so severe that for two years David was totally unable to come to terms with it or even talk about it. It was David's wife Julie who decided that the time had come to fight back. By forming an active group of fellow sufferers the two of them could provide much needed information and support to David and others in his situation.

The 'Support Group' was an immediate success.Fellow sufferers benefited from the companionship that the new group was able to offer. In 1993 Julie and David's 'Support Group' became the Psoriatic Arthropathy Alliance and the PAA, as it is known, was launched as a recognised nation-wide movement. To cope with the increasing demands of administration Julie, David's wife, left her job as a legal secretary and now works full-time (unpaid) for the PAA.

Do we really need yet another "good cause"?

Dear P.A.A.
I'm 27 years old and I have three children. I have had my PA for nearly six years now and I feel I am still not in control of it. It took three years for my PA to be diagnosed properly and even now I have difficulty obtaining any kind of literature or support . . . I don't know anyone who I can converse with . . . There seems to be nothing for young sufferers with PA. As you probably know this can make you feel very isolated . . . I am always told that there is no cure – at that point my whole life seems pointless . . . Does any of this sound familiar? Well I suppose I should leave it there and I'll be waiting for a reply to help with all this turmoil (if possible). . . . "

Letters such as this answer the question above. The P.A.A.'s experience is that effective help is best given by people who have particular experience and knowledge of this "Cinderella of all the rheumatic diseases"

Difficult to diagnose, impossible to pronounce

For most people the words Psoriatic Arthropathy are virtually unpronounceable. For sufferers that's the least of their concerns, but it's somehow symptomatic of a condition which is not only difficult to diagnose but one of the most unpredictable in its development and one of the most uncomfortable to endure.

Psoriasis is a chronic skin condition – a red, crusty, scaled, itchy rash on elbows, knees and scalp. Psoriatic Arthropathy, which may develop in some instances, causes pain and swelling in the joints and connective tissue. As a result, movement can be severely limited.

PA has been described as the "Cinderella of all the rheumatic diseases". Symptoms of PA differ so much from patient to patient that it's difficult even for a rheumatologist to understand and treat effectively.

A particular side effect is chronic fatigue and low quality of life. Since stress can make the problem worse, patients can experience a vicious spiral of increasingly severe symptoms and corresponding depression.

The American novelist John Updike and the playwright Dennis Potter have been two of the more articulate sufferers from PA, but almost every letter received by the PAA from sufferers includes a graphic and moving account of some of the difficulties and frustrations caused by this little-known condition.

The chronic fatigue and depression so often associated with PA make it vital for sufferers to have somewhere to turn for advice and support. Yet until David and Julie set up the Psoriatic Arthropathy Alliance there was no such organisation, exacerbating the feeling of isolation and loneliness that PA can impart. Now in its fourth year, the PAA has already helped literally hundreds of people.

The PAA provides information and advice, promotes self-help and encourages early diagnosis. It also seeks to raise awareness of PA and its associated problems, publishing information about PA, promoting the cause of further research and medical interest and campaigning for better treatments and management of the illness.

If the PAA had to identify the single most important reason for its existence it would say that "In the face of adversity and pain, in this Alliance there will always be friendship, support and a listening ear."

It is this caring commitment of the PAA that has already given a better, more hopeful outlook to so many of its members.

PA could affect up to three-quarters of a million people

Although Psoriasis is considered to be a minority illness, it is estimated that already up to three million people in the UK might be affected by this skin disorder. Recent studies suggest that, of these three million people, up to 25% (i.e. some three quarters of a million) will go on to develop Psoriatic Arthritis.

The fact that such a significantly large number of people is likely to have or to develop this chronic, incurable condition makes the work of the PAA all the more important.

The PAA produces and sends out regular Newsletters and Journals to its members, provides information sheets on a variety of topics, issues a contact list and arranges an annual conference, usually late in September of each year.

Now the PAA is Registered Charity No. 1051169

Once the PAA was set up and had proved its usefulness, David and Julie's next aim was to have the PAA registered as a recognised charity. By April 1996 they were able to launch it as the first charitable organisation dealing specifically with Psoriatic Arthritis, both nationally and internationally.

David Congdon MP hosted the launch in the splendid Jubilee Room at the House of Commons. Alastair Burt MP, Minister for Disabled People, also attended the event. In his opening speech David Congdon congratulated the PAA on acquiring charitable status, expressing the hope that this would mean increased awareness of what he described as "An important and . . . comparatively neglected area of care". He also paid tribute to David, Julie and the many friends and helpers who have contributed to the success of the PAA – "the sort of people who when they hit an obstacle don't give up but say to themselves 'How can we overcome it?' It is precisely this spirit of endeavour which is now making up for the previous lack of adequate information available to the newly diagnosed, the general public and medical practicioners. . . ."

If you would like advice from the PAA or if you would in any way like to contribute or help with its work, please phone Julie or David on **01923 672837** *or write to* PO Box 111, St. Albans, Herts AL2 3JQ.

To become a subscribing member of the PAA costs just £10 per year.

David Chandler (left) shows Alastair Burt MP, Minister for Disabled People, some of the literature specially prepared for the reception held in the Jubilee Room at the House of Commons on Thursday 18th April 1996

PAA BOARD OF DIRECTORS:

David Chandler, Co-Founder, Julie Chandler, Co-Founder,
Mr Patrick Parker, Mr Chris Friend, Ms Ann Dugdale, Mrs Kate Heath, Mrs Tricia Hobbs.
Dr A Virginia Camp, FRCP, Consultant Rheumatologist. Dr A White, MBChB, FRCP, D PhysMed, Consultant Rheumatologist.
Dr Sharon Jones, BM, MRCP, Registrar

PAA MEDICAL ADVISORS:

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Professor Christopher E M Griffiths, MD FRCP, Mrs Sherry Lynne Peters Dermatology Specialist Nurse

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Ms Elizabeth Ross, Clinical Research Assistant

RHEUMATOLOGY:

Dr A Virginia Camp, FRCP, Dr Douglas Golding, MA, MD, FRCPI, Dr Sharon M Jones, MRCP, Dr Neil McHugh, FRCP, Dr A White, MBChB, FRCP, D Phys Med

Independent Advisor to the PAA:

Mr R W Martin
Mr D. Edwards

LOOK WHO SIGNED THE VISITORS BOOK . . .

Dr.Virginia Camp	Consultant Rheumatologist
Dr.Sharon Jones	Senior Registrar, Rheumatology
Dr.Anthony White	Consultant Rheumatologist, Royal Free
Pro.Chris Griffiths	Dermatologist, Hope Hosp. Manchester
Ms.Elizabeth Ross	Clinical Research Ass. St.Barts Hosp. London
Dr.Anthony Chu	Consultant Dermatologist. Hammersmith Hosp.
Dr.H.Templeton	GP, Watford Herts.
Sister Pauline Wright	
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Ms Lesley Scott	Counsellor PR
Ms Kate Baillie	BSR/British League Against Rheumatism
Mrs Julia Aston	Aston & Co.,Chartered Acountants
Mr Patrick Hodson	National Eczema Society
Mr Patrick Parker	PAA Director
Mrs Kate Heath	PAA Director
Ms Tricia Hobbs	PAA Director
Ms Ann Dugdale	PAA Director
Mr Chris Friend	PAA Director
Mrs Julie Chandler	PAA Co-Founder/Director
Mr David Chandler	PAA Co-Founder/Director
Mrs Gill Mulliner	Genetic Interest Group
Mr Alastair Kent	Director, Genetic Interest Group
Mr Alan Kleiner	Marchday Trust
Mr John Dart	Director: D.E.B.R.A.
Ms Marjorie Johnson	ABPI
Mr John Ray	
Mrs Margaret Ray	Disability Times
Mr Berkeley Greenwood	Portcullis Research
Ms Sue Ward	National Eczema Society

PAA members:

Mrs P. Chandler
Mr P. Chandler
Ms Jill Flintham
Ms Sue Johnson
Mr John Byfield
Mr W.Deighton
Mrs Irene Deighton
Mrs Jackie Harvie
Miss Stephenie Harvie
Ms Sarah Hughes
Mrs Lyn Parker
Ms.Pam Connor
Ms. Paula Carter
Mr Brian Cross
Mrs Anne Cross
Mr John Bevan
Mr David Bevan
Mr Marc Leggett
Mr Keith Williams
Miss Sally Dale
Mr Geoff Dale
Mr David Uings
Mrs Cath Uings
Ms Anita Shapiro

MPS

Mr David Congdon	House of Commons
Mr Alistair Burt	Minister for Disability
Mr Eric Illsley	House of Commons
Mr John Marshall	House of Commons
Ms.Liz Lynne	House of Commons

. . and a few naughty ones who didn't sign the Guest book!

Liz Lynne MP *David Chandler* *John Marshall MP* *Prof. Chris Griffiths* *Dr. Tony White*

David Bevan *Marc Leggatt* *Dr. Virgina Camp* *Mr D. Congdon MP*

David Garmon-Jones. Merck Dermatology *Julia Aston Crouch & Co PAA Accountant* *Dr. Antony Chu Dermatologist Hammersmith Hosp. London*

PAA House of Commons Launch

Ms Ann Dugdale Director/PAA *Sally Dale Member & her father Geoff*

Peta Spibey British Health Professionals in Rheumatology *Mrs Anne Pendlebury Wrightington Hosp.*

PAA House of Commons Launch

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